



The CCHS Foundation

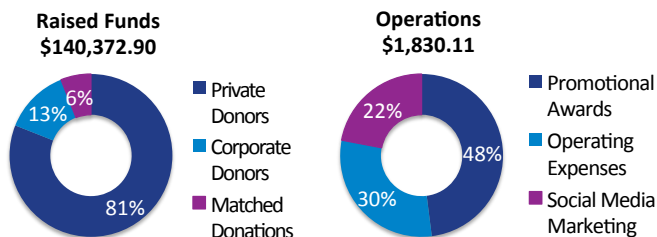
2015 Annual Report

Two thousand and fifteen marked the inaugural year of the CCHS Foundation and proved to be a time of recommitment, growth, and promise for the CCHS community. As an offshoot of the CCHS Family Network, the Foundation was designed to evolve years of advocacy and education into medical advances for our rare orphan disease. The CCHS community responded to this call for action through international fundraising, social media campaigns, donor expansion, and corporate partnerships. **The annual goal of \$100,000 was surpassed by 40%** through the incredible success of **International CCHS Day on November 14, 2015** as well as other initiatives and sadly, several memorials. The CCHS Family Network subsequently awarded its **first round of research grants** and established itself as an influential player in the research arena. The CCHS Foundation **sincerely thanks all of our supporters** who made this inaugural year one of **merit, validation, and hope**. Your work and devotion is transforming the future of 1200+ individuals who live each day being **BRAVE, RESILIENT, and DETERMINED**.

OUR MISSION

The aim of the Foundation is to raise money to **support CCHS research** (70% commitment), **continue CCHS educational outreach** (20% commitment), and **assist CCHS patients and families through the Ellen Whisman Fund** (10% commitment). To this end, we value integrity, transparency, accountability, collaboration, leadership, sensitivity, optimism, philanthropy, proactivity, and volunteerism.

THE INS & OUTS



PUTTING FACES TO THE NAME

The Foundation promoted visibility of CCHS by creating a dedicated **Facebook page with over 2700 followers**. CCHS was also featured in several film, video, and media forms in 2015. This included the **Academy Award nominated short documentary, *Our Curse***, which can be accessed on *The New York Times* website. The Foundation's **educational video has been played over 10 thousand times** in just four months and is available on www.CCHSNetwork.org. Several articles and news reports were also published as a result of community lobbying for greater awareness.

ON THE HORIZON

Research Award Announcement

June 2016

2nd Annual International CCHS Day

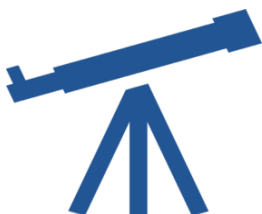
November 12, 2016

NORD Natural History Study on CCHS

2016-2021

CCHS Family Network Conference & International Research Conference

June 2018



MANPOWER

35

Parent and patient volunteers serve on our Foundation board, regional coordinators committee, and social media team.



MAKING THE CONNECTIONS

The CCHS Family Network & Foundation worked diligently to secure relationships with leaders in the rare disease community as well as prominent corporations and potential sponsors. Professional partners in 2015 included **Avery Biomedical, Martini Media Solutions, Jim Papoulis, AmazonSmile, Bravelets, GoodShop, and Kendra Scott Jewelry**. The CCHS Family Network enrolled as an **official member of the National Organization for Rare Diseases (NORD)**. CCHS was also the topic of the **David R. Cox Award for Rare Compassion**, an essay program that connects medical student with rare diseases.



CELEBRATING CCHS WORLDWIDE

The Foundation's greatest accomplishment of 2015 was the inception of **International CCHS Day**. Events took place around the world on November 14, 2015. Grassroots events included Dine and Donate gatherings organized by families. The Foundation held a **No-Show Virtual Pajama Party**, with 376 attendees, as well as a video game marathon. CCHS Day 2015 raised over \$78 thousand dollars and was deemed an overwhelming success in terms of advocacy and fundraising.

HASHTAGS OF HOPE

- #OURCURSEISOURCAUSE
- #CURECCHS
- #CCHSDAY2015
- #RAREDISEASEDAY
- #YOURCHANGEISOURCHANGE